Parliamentary Committees

Health and Community Services Committee

Inquiry into palliative care services and home and community care services in Queensland

Issues Paper **June 2012**

The purpose of this paper is to provide background to the inquiry by the Health and Community Services Committee of the Queensland Parliament into palliative care services and home and community care services in Queensland.

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1 Submissions invited

The committee invites individuals and organisations to make submissions on the issues in the terms of reference. Submissions close on **Monday 6 August 2012**. Submissions can be emailed or posted to the committee – see page 8 for details.

The committee welcomes submissions on any or all of the issues in the terms of reference. The information in this paper is not intended to limit comments on matters relevant to the terms of reference. The committee has the discretion not to accept submissions that are not relevant.

Guidelines for making a submission are on the Queensland Parliament website. The guidelines explain how submissions are dealt with, including publication and requests for confidentiality. See: http://www.parliament.qld.gov.au/work-of-committees/Guidelines/guidelines-general.

2 Terms of reference

On 7 June 2012 the Legislative Assembly resolved:

1. *That the Health and Community Services Committee inquire into and report on Queensland's chronic, frail and palliative care services.*

2. *That, in undertaking this inquiry, the committee should consider:*
   - *the capacity and future needs of these services (including children and adolescents palliative care)*
   - *the effectiveness, efficiency and adequacy of palliative, frail and chronic care services*
   - *examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services, and*
   - *consideration of segmenting the current Home and Community Service system based on age of the client, needs of the client, their carer and the providers.*

3. *Further, that the committee take public submissions and consult with key industry groups, carers, health workers and relevant experts.*

4. *The committee is to report to the Legislative Assembly by 28 February 2013.*

Section 9 of this paper summarises current reforms that are relevant to the terms of reference.

2.1 What will the committee examine?

The committee will consider the capacity and future need for palliative care and HACC services including service effectiveness, efficiency and adequacy; and opportunities to improve collaboration and cooperation between services and the disability and health sectors.

Specifically, the committee will inquire into the following:

- palliative care services in a variety of settings, including hospital, hospice, home, community and aged care facilities and palliative care services for children and adolescents
- home and community care services, including home nursing, respite care, delivered meals, transport, home maintenance, palliative care and other care services. The committee will also consider the segmenting of home and community care services based on the client's age, needs, their carer, and the care providers.
- opportunities for reform to improve collaboration and cooperation between chronic, disability and other health services.

Hospital services and residential care services for people who are frail, or have a chronic condition or disability will be considered when the committee examines palliative care services and opportunities to improve coordination and collaboration between chronic, disability and other health services.

2.2 Matters outside the scope of the inquiry

The committee's terms of reference do not include euthanasia or the prevention and treatment of chronic disease.

3 Palliative care services

3.1 What is palliative care?

The term 'palliative care' is sometimes used to mean 'specialist palliative care' or 'end of life care'. The committee uses the World Health Organization (WHO) definition, which recognises that palliative care may be provided by non-specialists. This definition is also used in the *National Palliative Care Strategy.* [1]

Palliative care is defined by the World Health Organization as:

> *…. an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*
>
> *Palliative care:*
>
> - *provides relief from pain and other distressing symptoms*
> - *affirms life and regards dying as a normal process*
> - *intends neither to hasten or postpone death*
> - *integrates the psychological and spiritual aspects of patient care*
> - *offers a support system to help patients live as actively as possible until death*
> - *offers a support system to help the family cope during the patients illness and in their own bereavement*
> - *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
> - *will enhance quality of life, and may also positively influence the course of illness*
> - *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*[2]

3.2 Who provides palliative care?

Palliative care is provided by many health and care professionals in diverse settings. Care providers include specialist palliative care physicians, general practitioners, nurses (specialist and generalist), allied health professionals, aged care workers, other care providers and family and friends. Services may be delivered in hospitals, hospices, the patient's home or elsewhere in the community.

4 Home and community care services

4.1 What are home and community care services?

Home and community care (HACC) services are funded jointly by the Commonwealth and State Governments. Services aim to support people over 65 and younger people with a disability and carers to be more independent at home and in the community. By providing basic support services,

1 *National Palliative Care Strategy 2010 - Supporting Australians to Live Well at the End of Life*, ibid

2 World Health Organization (WHO), http://www.who.int/cancer/palliative/definition/en/

the HACC program aims to enable people to live at home and reduce the potential for inappropriate admission to residential care.

HACC services include: nursing care; allied health care; meals and other food services; domestic assistance; personal care; home modification and maintenance; transport; centre based day care; respite care; counselling, social support, information and advocacy; and case management and assessment.

4.2 Who provides HACC services?

The Department of Communities, Child Safety and Disability Services is responsible for funding and regulation of HACC services in Queensland. Services are delivered primarily by non-government organisations (NGOs), which include large NGOs that deliver services in a number of locations, and small locally based NGOs. Some services are delivered by local councils, Queensland Health and community health services. Most HACC service providers deliver services to frail aged people (funded by the Commonwealth from 1 July 2012) and to younger people with a disability (funded by the Queensland department).

5 Capacity and future needs for palliative care and HACC services

5.1 Service capacity

The capacity and sustainability of services is influenced by a broad range of factors. They include the level and type of need for services, a skilled health and care workforce in the right locations, the level of resources available, service integration, coordination and collaboration and the use of technology to support service delivery.

The committee is particularly interested in receiving submissions which describe innovative ways to develop a sustainable palliative care and community care system in Queensland to meet current and future needs.

5.2 Future need for services – ageing population

The ageing population and increased life expectancy will result in a growing level of need for palliative care and HACC services.

In mid 2011, 14% of Australia's population was aged 65 or older. By 2031, the Australian Bureau of Statistics predicts that 19 – 21% of the Australian population will be 65 or older. [3]

The Australian Bureau of Statistics has projected that the Australian population will grow by 29% over the 20 years from 2010. The number of people aged 65 and over is projected to rise by 91%, and the number aged 81 and over is expected to more than double.[4]

Increased life expectancy means that a higher proportion of people are expected to live with, and die from chronic progressive diseases. Those people are more likely to be consumers of home and community care services and palliative care services. Significant increased need for those services is therefore expected.

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3 ABS Population projections Australia 2006-2101. ABS.cat.no.3222.0 Canberra. 2008.

4 ABS Australian demographic statistics, March 2011. ABS cat. no. 3101.0. Canberra
AIHW, ibid, p 51

6 Effectiveness, efficiency and adequacy of palliative care and HACC services

Improved life expectancy and a larger cohort of older people in future years mean it is unlikely that future needs will be met without reform and improvements to the way that palliative care and HACC services are delivered.

The inquiry terms of reference include consideration of the effectiveness, efficiency and adequacy of services. The committee is interested in information about research on the effectiveness of palliative care and HACC services and information based on the experience of consumers and service providers.

Emerging technologies, particularly tele-health and the use of electronic health records may create opportunities to improve the effectiveness and efficiency of services delivered in the home.

The issues of potential interest to the committee include: factors that enable effective and efficient service delivery; barriers to effective palliative care and HACC services; consumers' preferences for how and where services are delivered; unmet needs for services; innovative service delivery arrangements; and models of cost-effective and quality service delivery.

The committee also welcomes comments on other issues that influence the effectiveness, efficiency and adequacy of palliative care and HACC services.

7 Improving integration, collaboration and cooperation between palliative care, HACC, disability services and other health services

The health, aged, disability and community services systems are complex, confusing and difficult to navigate. Consumers sometimes do not have timely access to services that they need and have limited choices about types of care service available. Some consumers, particularly older frail people, and people with chronic conditions receive unwanted interventions or are admitted to hospital unnecessarily.

Some of the measures that have been proposed or implemented to improve integration and collaboration between home care, disability, palliative care and other health services include personalised electronic health records, more consumer-directed care, Medicare Locals, greater use of multi-disciplinary teams, expanded hospital in the home services, and greater involvement of general practitioners.

The committee is interested in hearing from consumers, service providers and others about initiatives to improve service integration, collaboration and cooperation. In particular the committee would like to hear about innovations, successful models of coordination and potential improvements that could be made through the local management of hospitals and health services in Queensland.

8 Segmentation of the HACC system

The terms of reference include consideration of separating the HACC system based on the age of the client, the needs of the client, their carer and the service providers. Changes in the HACC system to separate funding and regulatory responsibility for services to clients aged 65 and over, or under 65 are outlined in section 9.2 below.

The committee is interested in comments on the anticipated impact of the separation of HACC services according to age on Queensland consumers and service provider organisations, including the

impact on existing clients as they approach the age of 65. The committee will seek further comment from stakeholders on the impact of the separation of funding responsibilities later in 2012.

Comments are also sought on segmentation of the HACC system according to clients' needs, client's carers, or service providers.

9 National policy context - health system reforms and policies

Health services in Queensland and the rest of Australia are undergoing significant change as part of the national health reforms that were agreed between the Commonwealth and State and Territory Governments through the Council of Australian Governments (COAG).

The current national health reforms are underpinned by the *National Health Reform Agreement* (NHRA) which was signed in July 2011.[5] Health system changes under the NHRA are being implemented over several years. Those that are potentially relevant to the committee's inquiry are summarised below.

9.1 Decentralised management of public hospitals and health services

The establishment of localised governance to decentralise public hospital management and increase local accountability is to take effect under the NHRA on 1 July 2012. New Queensland legislation [6] will establish 17 Hospital and Health Services (HHS) to replace the former Health Service Districts. The new HHS will be statutory bodies managed by boards of at least five members appointed by Governor in Council.

Hospital and Health Services will enter into service agreements with Queensland Health about funding, the services they will provide, performance measures and related matters. The chief executive of Queensland Health will be the system manager, and may issue directives to HHS to promote service co-ordination, integrated service delivery, optimise the efficient use of resources and related matters.

9.2 Aged care and disability services

9.2.1 Productivity Commission inquiries

In 2011 the Productivity Commission reported on its inquiry into Caring for Older Australians[7] and recommended reforms in both residential aged care and community care.

The report of the Productivity Commission's inquiry into Disability Care and Support described the disability support system as "underfunded, unfair, fragmented, and inefficient" [8] and recommended the establishment of a National Disability Insurance Scheme.

9.2.2 Changes to funding arrangements

Commonwealth and State funding responsibilities for aged care and disability services are being separated on 1 July 2012. The Commonwealth is responsible for funding and regulating services for people aged 65 and over (50 and over for Indigenous people). The State's responsibilities include disability services, community care services, packaged community and residential aged care[9] for people under the age of 65. The separation of responsibilities is not intended to result in any change

5 The *National Health Reform Agreement* and other intergovernmental agreements are available on the COAG website at http://www.coag.gov.au/

6 The *Health and Hospitals Network and Other Legislation Amendment Act 2012* was passed on 20 June 2012. Subject to the Bill receiving assent, the amended *Hospital and Health Boards Act 2011* is scheduled to commence on 1 July 2012.

7 Productivity Commission, Caring for Older Australians. 2011. http://www.pc.gov.au/projects/inquiry/aged-care/report

8 Productivity Commission, *Disability Care and Support*. Productivity Commission Inquiry Report No. 54, 31 July 2011, Executive Summary, p 3. 2011 http://www.pc.gov.au/projects/inquiry/disability-support/report

9 Some people aged with high care needs who are under 65 live in nursing homes (residential aged care facilities)

for clients. Under the NHRA and the National Partnership Agreement[10] responsibility for providing continuity of care to ensure smooth client transitions is shared by the Commonwealth and State.

9.2.3 Home and community care services

Funding responsibility for the HACC program will be separated according to clients' age from 1 July 2012. In Queensland the Department of Communities, Child Safety and Disabilities provides funds to organisations to deliver HACC services; it will fund services for people under the age of 65, and the Commonwealth Department of Health and Ageing will fund services to deliver HACC services for people aged 65 and over.

9.2.4 Proposed national disability insurance scheme

The 2011 Productivity Commission report on Disability Care and Support recommended a national disability insurance scheme, which would rely significantly on the provision of home based services to meet the specific needs of an individual with a disability. Proposals for an insurance scheme are under discussion between governments, and while an outcome is not yet clear, it is likely that the priority for care services for people with disabilities will continue to be for home based services which maximise a person's independence and ability to live in the community.

9.3 National palliative care strategy

State, Territory and Commonwealth Health Ministers endorsed the *National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life* in November 2010. The Strategy recognises that the demand for high quality palliative care services will inevitably increase, and that palliative care services are provided in almost all parts of the health and human services sector. To meet increasing demand, the Strategy focuses on four goal areas:

- *awareness and understanding* of dying, death, grief, bereavement and loss, to support better access to appropriate, timely services
- *appropriateness and effectiveness*, ensuring the right approach, at the right time in the most suitable setting; providing services that are supported by evidence and meet the needs of patients and their families
- *leadership and governance,* to ensure implementation and improvement of services; in a diverse service system strong accountable leadership and governance is particularly important
- *capacity and capability* to provide effective care services by having sufficient skilled people in the right place with systems to support high quality care, and sufficient resources, facilities and equipment to deliver care.

The National Palliative Care Strategy further defines those four goals and suggests measures of success.[11]

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[10] *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*, 2011, http://www.federalfinancialrelations.gov.au/content/national_partnership_agreements/community_services.aspx

[11] *National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life*. Commonwealth of Australia. Canberra, at http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/NationalPalliativeCareStrategy.pdf

10 Committee report

The committee is required to report to the Legislative Assembly by 28 February 2013. The report will be tabled in the Legislative Assembly and published on the committee's website. The *Parliament of Queensland Act 2001* requires the responsible Minister to respond to a parliamentary committee's recommendations within three months of the committee's report being tabled. The Minister's response is tabled in the Legislative Assembly.

11 Health and Community Services Committee

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Deputy chair

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Mr Aaron Dillaway MP, Member for Bulimba

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